News focus

Iceland plans reigned in

Michael Gross looks at the problems that beset plans for the country's pioneering genome project.

Back in 2000, when the imminent completion of the human genome fired the imagination of many biotech entrepreneurs and the internet bubble had yet to burst, many people were considering the logical next step after the genome. After establishing the three billion letters of DNA code that we all have in common, the hunt was on for the much smaller number of letters that are variable between individuals and that are held responsible for a range of problems, from inherited disease through to different responses to prescription drugs.

Projects that sought to link medical, genealogical and genetic information in an attempt to crack the code of human genetic variability were seen shooting up everywhere, using small gene pools like isolated Italian villages or larger ones, like the entire nations of Iceland and Estonia (Curr. Biol. (2001), *11*, R1).

One of the earliest starters in the new field of pharmacogenomics was the Icelandic genome project, masterminded by geneticist Kari Stefansson and spearheaded by his company Decode Genetics. Stefansson managed to enthuse politicians and large parts of the general public in Iceland with his promises of turning the peculiarities of their nation — few founders, long isolation, good genealogical record-keeping — into biotech gold. By buying shares in the company, all Icelanders would be able to make a profit from the research into their own genetic heritage. As early as 1998, after intensive public debate, the Icelandic parliament approved a bill enabling the establishment of a central medical database, where medical information was to be linked with genealogical details and gene sequences obtained from blood samples.

As a result of the public debate, a watchdog was created to control the power of Decode over the participants. While the default option was that all medical records would be included in the database, everybody who wished to do so could opt out of the project. Given these precautions and the highly democratic process that led to this arrangement, what could possibly go wrong?

By 2002, however, the Icelandic genome bubble had burst on the stock market. Maybe politicians and biotech entrepreneurs made more promises than they could keep in the short term, or maybe the hype generated by an

Side step: Plans for a national genomics database for Icelanders have faltered. (Photo: Johannes Long/Photolibrary.)

excess of public enthusiasm for the project just became a fatal stampede. The fact of the matter is that the shares in Decode that were traded on the unregulated Icelandic market at that time went to unrealistic heights of over $60, and then collapsed dramatically to the area of well below $6.

Even though Decode has reported some scientific progress since that time, including the discovery of gene variants responsible for some cases of prostate cancer, schizophrenia, and cardiovascular disease, the company's financial fortunes never fully recovered from this crash. At the time of writing, NasDaq listed Decode shares trade at $4.97, nearly 50 per cent down from the price one year earlier.

With the economic downturn and the newspaper reports about small investors ruined by it came a growing concern about the privacy issues. More and more Icelanders made use of their right to opt out of the medical database. Court cases were fought, and press reports have now pronounced the national medical database as dead. Decode's press department has pumped out more than 40 press releases so far this year, not one of which has a topic related to the medical database that everybody talked about earlier.

Instead, Decode has turned into a more traditional biotech company and focused on drug discovery based on a few links between gene variants and common diseases that it has discovered so far. Products in its development pipeline include a drug for patients with specific genetic risk factors for heart attacks (phase III) and one for the treatment of peripheral artery disease (phase II). The change of direction is underlined by a few top-level appointments the company made this year, including that of Peter Goodfellow (formerly GlaxoSmithKline) to its board of directors. Genomics is likely to take a new turn here now.

Michael Gross is a science writer based at Oxford. He can be contacted via his web page at www.michaelgross.co.uk

UK banking on consent

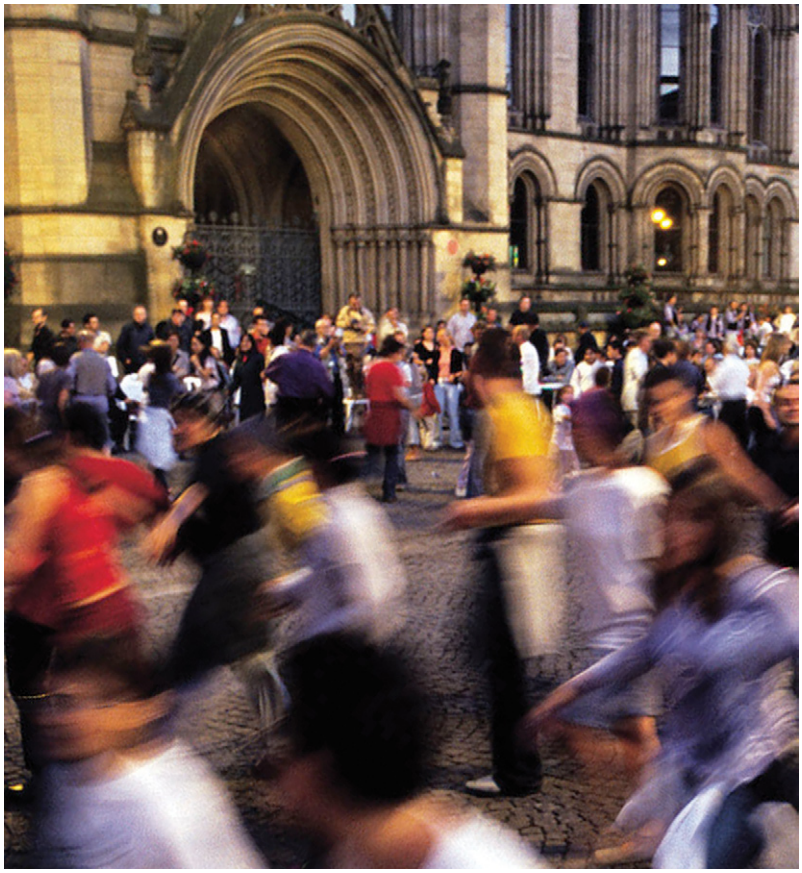
Britain has won both academic and public support for a major human genomics and health project. **Nigel Williams** reports.

A UK project to study genetics alongside health and lifestyle data, piloted in Manchester, has proved a success in no small part to the specific consent sought from participants by researchers. This pilot has now turned into the largest study of the genetic and environmental causes of disease rolled out across the UK. The UK Biobank aims to obtain DNA samples from up to 500,000 people aged 40–69 and track their health. It is hoped the database will be used to find cures for killer illnesses such as heart disease, diabetes and cancer. The project received unanimous support from a team of international experts and its backers this summer following the Manchester pilot.

Letters will be sent to men and women in the target group by the end of the year, inviting them to attend one of a network of assessment centres to be set up in locations around the UK. Over the next three to four years, there will be around 35 centres in the UK, each open for about six months. The centres will be located in areas where there are about 150,000 men and women aged 40–69 living within a 15 kilometre radius.

The project will gather, store and protect a vast bank of medical data and material. The aim is to give accredited researchers a rich resource which they can use to examine how the complex interplay of genes, lifestyle and environment affects our risk of disease.

The £61 million project is being funded by the Medical Research



Agreed: Support from people in Manchester in the pilot study has boosted the plan to go national for a long-term genomics database. (Photo: Marketing Manchester/ David Oates.)